

Senate Bill No. 1503

CHAPTER 409

An act to add Chapter 7.5 (commencing with Section 104323) to Part 1 of Division 103 of the Health and Safety Code, relating to Amyotrophic Lateral Sclerosis.

[Approved by Governor September 27, 2008. Filed with
Secretary of State September 27, 2008.]

LEGISLATIVE COUNSEL'S DIGEST

SB 1503, Steinberg. Public health: Lou Gehrig's disease.

Existing law provides for regulation and licensing of health care service plans by the Department of Managed Health Care. Existing law requires every health care service plan, except a specialized health care service plan, to establish and implement procedures by which an enrollee could receive a standing referral, as defined, to a specialist and by which an enrollee with a condition or disease that requires specialized care over a prolonged period of time and is life-threatening, degenerative, or disabling could receive a referral to a specialist who, or a specialty care center, as defined, that, has expertise in treating the condition or disease for the purpose of having the specialist, or the specialty care center, coordinate the enrollee's health care.

This bill would declare that an ALS Association Certified Center is a specialty care center for this purpose.

Existing law provides for programs administered by the State Department of Public Health for the prevention and treatment of various diseases.

This bill would make legislative findings regarding Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, and its treatment.

The people of the State of California do enact as follows:

SECTION 1. Chapter 7.5 (commencing with Section 104323) is added to Part 1 of Division 103 of the Health and Safety Code, to read:

CHAPTER 7.5. AMYOTROPHIC LATERAL SCLEROSIS (ALS)

104323. The Legislature finds and declares all of the following:

(a) Amyotrophic Lateral Sclerosis (ALS), more commonly known as Lou Gehrig's disease, is a degenerative disease of the motor nerves that causes progressive weakness of all voluntary muscles. People with ALS become unable to move, swallow, speak, and breathe without assistance, usually remaining fully aware of what is happening to them and to their families.

(b) ALS is a fatal disease. Most ALS patients die within two to five years of symptom onset. Every 90 minutes someone is diagnosed with ALS and every 90 minutes someone dies of the disease. ALS knows no racial, ethnic, or socioeconomic boundaries, often striking people at midlife and at the height of family and financial responsibilities.

(c) The devastating physical, emotional, and financial effects caused by the progression of ALS and the 24 hour a day, seven day a week caregiving required impacts not only the patient, but the entire family. ALS is a family disease.

(d) For many patients, the one drug approved by the federal Food and Drug Administration for the treatment of ALS shows little, if any, efficacy in slowing the progression of the disease. As a result, the focus of intervention for ALS patients is managing the effects of the disease progression. Research has shown that aggressive multidisciplinary care, provided within a collaborative environment, can extend a patient's life, reduce hospital admissions, and improve the quality of life for the patient and family. Ultimately, though, more research is needed to find an effective treatment and cure for ALS.

(e) To significantly extend and improve the quality of life of people living with ALS, the state recognizes the need for the California System of Care for ALS Patients model based upon the principles described in subdivision (f).

(f) According to the American Academy of Neurology (AAN), the mainstay of treatment for ALS patients is symptom management. As a result, the AAN has established a practice parameter for the care of ALS patients. These guidelines establish a foundation on which to develop a system of care that enables the delivery of a comprehensive array of services critical to the care of ALS patients and their families. The AAN sets this foundation in their four principles of ALS management summarized as follows:

(1) High priority should be placed on patient self-determination and the delivery of both information and care must take into consideration the cultural and psychosocial context of the patient and family.

(2) Patients and families need information that is timed appropriately for decisionmaking.

(3) The physician, in conjunction with other health care professionals, should address the full continuum of care for the patient with ALS.

(4) Discussions regarding advance directives should be introduced and periodically reevaluated to ensure that ALS patients and their families understand the issues to be faced in the terminal phase of the disease.

(g) The services described in subdivision (f), when delivered through a highly coordinated effort, form a model program designed to provide the highest level of care available for the successful management of the needs of ALS patients and their families.

(h) ALS Association Certified Centers (centers) are a vehicle for state-of-the-art multidisciplinary and interdisciplinary care and management of ALS. The centers reflect four main objectives:

- (1) The involvement of all necessary health care disciplines in the care of the ALS patient and his or her family.
- (2) The offering of multidisciplinary and interdisciplinary care, regardless of the ability to pay.
- (3) Collaborative work among centers to enhance ALS patient care techniques.
 - (i) Centers provide a one-stop shop at which the patient and family have access to a team of health care professionals from every specialty area that they may need during the progression of ALS. Each professional is an expert in ALS as well as his or her own field. The team that assesses and treats patients during their visits to a center includes individuals in all of the following specialty areas:
 - (1) Physical therapy.
 - (2) Occupational therapy.
 - (3) Respiratory therapy.
 - (4) Nursing.
 - (5) Registered dietitian services.
 - (6) Psychology or psychiatry.
 - (7) Speech and language pathology.
 - (8) Medical social work service.
 - (j) An ALS Association Certified Center is a “specialty care center” for the purposes of Section 1374.16.